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AUTHOR Ooms, Theodora; Owen, Todd
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ABSTRACT

This report contains highlights from a seminar on the role of parents in helping adolescents with their health problems. Comments by these panelists is summarized: Judy Areen, dean, Georgetown University Law Center; Barbara Popper, founder and board member of Children in Hospitals, Inc. and resource specialist at the Federation for Children with Special Needs; Vernon Oakes, professor of marketing at Howard University, and member of Toughlove; and Naomi Karp, second vice-president, Federation of Families for Children's Mental Health, and partner in Family and Integration Resources. These topics, discussed at the seminar, are summarized: (1) exceptions to the parent consent presumption; (2) parent notification in minors' abortion; (3) issues in health care for special needs adolescents; (4) Toughlove and Toughlove for minorities; and (5) the Federation of Families for Children's Mental Health. A background briefing report is also included which contains information about the special challenges of adolescent treatment; a legal framework; difficult clinical dilemmas; parents' roles in adolescent health and medical treatment; chronic physical illness and disability; the contribution of the parent movement; the role of public policy; and selected parent self-help organizations. (40 references) (LLL)

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Parents' Role in Teenage Health Problems: Allies or Adversaries?

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Parents' Role in Teenage Health Problems: Allies or Adversaries?

September 21, 1990, Mansfield Room (S. 207), the U.S. Capitol

Panelist: **Judith Areen, J.D.,** dean, Georgetown University Law Center
Barbara Popper, founder and board member, Children in Hospitals Inc., and resource specialist, Federation for Children with Special Needs
Vernon Oakes, M.B.A., marketing professor, Howard University, and member, Toughlove
Naomi Karp, second vice-president, Federation of Families for Children's Mental Health, and partner in Family and Integration Resources

Moderator: **Theodora Ooms,** director, Family Impact Seminar

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Parents' Role in Teenage Health Problems: Allies or Adversaries?

Background Briefing Report
and
Meeting Highlights

Theodora Ooms and Todd Owen

This policy seminar is one in a series of monthly seminars for policy staff titled, *Family Centered Social Policy: The Emerging Agenda,* conducted by the **Family Impact Seminar,** American Association for Marriage and Family Therapy, Research and Education Foundation, 1100 Seventeenth Street, N.W., The Tenth Floor, Washington, D.C. 20036, 202/467-5114.

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Parents' Role in Teenage Health Problems: Allies or Adversaries?

Highlights of the seminar meeting held on September 21st, 1990, Mansfield Room, S.207 in the U.S. Capitol. (A supplement to the Background Briefing Report.)

There is growing concern among policymakers and professionals about adolescents' health and health problems. Theodora Ooms, the moderator, emphasized that today's seminar focused on a much neglected topic, namely what role parents play in helping teenagers with their health problems---are they allies or adversaries?

Ooms introduced the first speaker, Judy Areen who is Dean of the Georgetown University Law Center and author of a widely used textbook on family law. Areen was asked to provide a basic framework of the law with respect to adolescent health, and parent consent and notification.

According to Areen, summaries of the law on adolescent health care typically state that there is a long history of common law requirements for parental consent for all medical procedures and that only recently have legislatures tinkered with this uniform, common law approach.

Areen said that there are some problems with this interpretation of history. The legal requirement that doctors should obtain consent for medical procedures from patients, even when adult, has been enforced regularly only in this century, and the concept of informed consent is even more recent. Similarly, the view that parents used to have total control over their children's health but now they don't, ignores both legal precedents and the views of some of the major figures who have shaped our modern views on the appropriate balance between the rights of the individual and the family, such as John Stuart Mill, John Locke and the jurist Blackstone.

Areen added, "the complexity of the current status of the law is not just a result of the fact that we have 51 different state legislatures and court systems that wrestle with these problems but also reflects an ongoing philosophical and legal debate that's been with us for more than three centuries."

Exceptions to Parent Consent Presumption. Areen cited the recent working paper by Gittler, Quigley-Rick and Saks (1990) which presents a very useful review and taxonomy of the current status of state laws on this subject. The authors found there were two categories of exceptions to the general rule that you must have parental consent for health care. The first category which Areen dubbed 'boundary maintenance' deals with the capacity or characteristics of certain individual adolescents to consent to health care themselves without parent's consent. This group includes 'emancipated' minors, a category defined somewhat differently in each state but usually meaning married minors, those serving in the military and so forth and psychologically 'mature' minors. This concept of exception for 'maturity' was affirmed by a Supreme Court decision in 1979 in an abortion case.

The second category of exception involves the type of treatment being provided and thus rests on a public health rationale rather than on the individual capacity of specific minors. Usually specified in these types of exceptions is treatment related to family planning, pregnancy, sexually transmitted diseases, drug and alcohol abuse, and mental health services. (The rationale is that society has an

interest in removing any barriers---such as parental consent---to the teens receiving treatment for these problems.)

Because these laws are in flux it is hard to make general statements about patterns across the country, moreover the specific requirements vary considerably from state to state. These laws did not evolve from a long history of court decisions but rather from pressures in the political arena and as such could be changed tomorrow. Areen proceeded to summarize three important recent Supreme Court decisions.

- **Parent Notification in Minors' Abortion**. No aspect of this matter has received more attention than the issue of abortion. The most recent Supreme Court decision on abortion, *Hodgson v. Minnesota,* concerned a statute that required the notification of both parents before a minor receives an abortion. Two versions of the statute were written so that if a court were to rule the first, preferred, version unconstitutional, the alternative would retain the two parent notification but include a judicial bypass procedure to be available to mature minors or those for whom notification would not be in their best interests. The court was divided 4-4 with Justice O'Connor in the middle ruling that while the first version was unconstitutional the alternative statute, with the judicial bypass should be upheld. Thus this is the current law of the land on this issue. Yet with the retirement of Justice Brennan, Justice O'Connor may no longer be the swing vote on this issue and this makes the status of the law on parent notification very uncertain.

- **Parents' Right to Commit Minors to Inpatient Treatment.** In a 1979 Supreme Court decision, *Parham v. J.R.*, the court ruled on the parents' right to civilly commit their child for mental health (inpatient) treatment. Chief Justice Burger wrote that the law presumed that "parents possess what a child lacks in maturity, experience, judgement and capacity required for making life's difficult decisions"... and that "the notion that governmental power should supersede parental authority in all cases because some parents abuse and neglect their children is repugnant to the American tradition." This statement pretty much sums up the American tradition of deference to parental authority.

- **Mature Minors' Right to Refuse Treatment.** The third case took place in Illinois and involved a 17 year old Jehovah's Witness with acute leukemia who was refusing a blood transfusion which would save her life. A lower court ruled that the concept of privacy of a mature minor used by the Supreme Court in abortion decisions applied to this case. On appeal the Illinois Supreme Court upheld the minors' right to refuse treatment not on a constitutional rationale but because they found it explicit in the common law of the state of Illinois. (This parallels the Supreme Court's decision in the Cruzan decision which deferred to state law on the question of adult's right to consent.)

In summary, Areen said health care today is dominated by state statutory law much of it reflecting a public health rationale rather than taking a position on this difficult issue of how much to include parents of minor children in decision making. Abortion has been the primary arena with courts favoring parental involvement as long as there is judicial bypass.

Areen concluded that the "1990s are likely to be an era of greater deference to state legislative decision making in this as in so many controversial matters. It is where we will see a continued wrestling with the issue of individual (minor's) capacity on the one hand and individual rights vs. public health needs on the other."

Barbara Popper, the second speaker, is founder and board member of Children in Hospitals, Inc. and works as a resource specialist at the Federation for Children with Special Needs, one of the oldest, most active of the parent organizations concerned with the needs of chronically ill and disabled youngsters.

Popper began by saying that although her original interest was in the rights of parents of young children to be involved in their hospitalization, it is clear that ill children of any age are equally in need of their parents. She wondered whether the question---are parents allies or adversaries?--- referred to parents' relationship with their child or the health care system. Her response was that families need to work with the system and try to avoid controversy and conflict in alliance with their children.

Issues in Health Care for Special Needs Adolescents. Between 5-10% of American teenagers have special health needs. But they also face most of the typical problems and issues all adolescents face and therefore should not be separated from other programs. And teens with special needs themselves have a great need to be treated like everyone else.

Like other adolescents they are moving towards independence from their parents, but they also want to be reassured that their parents are still there for them. They want to take over responsibility for taking their medication and their treatment. But this can create problems. Teenagers are risk-takers and are frequently more concerned with "fitting in" with their peers than with their health thus they may put themselves in jeopardy by forgetting their medication or restrictions. They may not mention pain or symptoms or ask for help when they need it. Thus parents still often have to be advocates and provide the information for their teens. They are caught between delight for their children taking control of their own lives and fear of the dangers of encouraging too much independence too soon.

Many teens are very uncomfortable getting care in pediatric settings. But where are they going to go for treatment? If they go to adult settings, the health care personnel may be quite unused to dealing with their special needs---it is only quite recently that children with, for example cystic fibrosis, lived to adulthood. Moreover these facilities -big medical centers- are tertiary based, not community based, which is more alien to teens. There is a need for an adolescent care system to fill the void between adults and pediatric care, and to ease transitions into the adult medical system.

Are the caregivers the allies or adversaries of the parents? They don't always know how to deal with the families of teens. Parents' motives for wanting to be involved are often suspect. Who should health care professionals talk to---the parent or the teen? If they talk only to the teen will she/he be reluctant to disclose certain information, or agree to certain suggestions too readily? Are the caregivers skilled at balancing the teens' needs for privacy, to be involved in the decisions and to become more responsible for their treatment with the fact that parents still need to provide information, be informed, sign consents until age 18 and be involved as their child's advocate? Many providers are not very skilled at working in partnerships with parents and teens as a team. In addition the legal ambiguities described by Areen add to the confusion.

Professional caregivers need to be trained to realize that disabled and chronically ill teens also confront issues and problems all teens have to face, such as drug and alcohol use and sexuality. In addition caregivers must discuss with teens and their parents realistic future planning about what is possible for them given their illness or disability with respect to college, work etc and independent living. What tasks can teenagers gradually take on themselves? And there are some children, who are so seriously disabled, that they are always going to be dependent on their parents, in these situations parents need to be appointed as guardians after they become 18 as they will always be involved in their care.

State and Federal Efforts. At the Surgeon General's workshops on issues for children with special health care needs held in 1985 and 1987 the goals for family-centered, community-based coordinated care for these children were firmly spelled out. The core concept of this philosophy, articulated well in a monograph and some brochures published by the Association for the Care of Children's Health is the recognition that the family is the constant in the child's life while the

service systems and the personnel within those systems fluctuate. It also recognizes family strengths and individuality and respect for different methods of coping. Popper cited the P.L. 99-457, Zero-to Three law, as an example of a law based on these principles. Families who have grown up with this law will approach their children's adolescence with a set of very different expectations of health care providers. (See Ooms, T.& Herendeen, L., 1990, below.)

As an example of what state governments can do in this area Popper described activities in her home state. Massachusetts' Health Department is sponsoring networking opportunities for parent groups, using parents as advisors and consultants and using money to support parent organizations' efforts. It is hoped, Popper concluded, that the Title V reauthorization bill, which will direct funds for family-centered community-based care will help solidify the role of parents as allies with the health care system as they continue "working towards a common goal of helping these kids become as safe and independent as is possible for them."

Vernon Oakes teaches marketing at Howard University. He is a member of Toughlove, an international self-help organization for parents of substance abusing and out of control teenagers and recently started a Toughlove support group in Washington. He was asked to describe some of the painful issues facing these parents, how the support group process helps parents rebuild their families and its potential for minority families.

Personal Experience. Oakes began by describing the events of the last eight years of his life which led him to Toughlove. One day eight years ago when his family was living in Puerto Rico, Oakes said his thirteen year old son was found shooting a BB gun at the neighbors. His son said he was shooting at them because "they looked at him strangely." To his surprise today, Oakes said he accepted this excuse and it wasn't until four years later that he began thinking that drugs were a factor in his son's many behavioral changes. This denial he said "is a disease as bad as drugs for parents, children, and people on drugs."

Oakes moved his family to Washington, D.C. and, after more brushes with the law his son was placed in the Glen Mills detention center and did very well, was state champion in power lifting and got his GED, and graduated in March 1988. By that summer his son was wanted by the police for armed robbery and skipping bail and had started smoking crack. In December 1988 he was jailed in Montgomery County for shoplifting. Oakes' daughter bailed his son out of jail and he came home two days before Christmas. By this time Oakes said he finally suspected his son was using drugs and would skip bail so on December 24 he decided to call the police and have his son arrested. "This was really tough on me."

In January Oakes' son applied for treatment with the Second Genesis program. In June he was informed that Second Genesis would have an opening in six months. Other programs were much too expensive and at that time Oakes didn't have insurance. Oakes helped to get his son out of jail in August after his son had shown the desire and initiative to get treatment. A month later his son was on the streets again. This was especially frustrating because his son had tried very hard to get help. Oakes went to Toughlove in October and in November, with the help of Toughlove, got his son into a treatment program for a month in Alabama, which Oakes also participated in with his daughter.

Oakes said that clearly there are not enough treatment programs. But equally important is that there should be a choice between public (free) programs and high price programs---parents should be able to contribute towards the cost of a program according to their income.

The Benefits of Toughlove. Oakes joined the Toughlove program in Mc Lain, Va. because there wasn't one in D.C. At this meeting there were one or two blacks and the rest (30 - 50

parents) were "white. He began to realize that, while not highly publicized by the media, this is an issue with no class, race, or geographical boundaries. He got a lot of support from people who understood his problem and didn't blame him. They introduced him to various treatment programs and he was finally able to get his son into a program for a month. He decided that when he felt he was ready he would organize a group in D.C.

Phyllis and David York, themselves counselors, started the program after their daughter got heavily involved in drugs. They found what really helped them was support from neighbors. They then developed the support group program which is now nationwide and subsists almost entirely from the sale of the manuals and other publications. (For details see page 23)

Oakes mentioned the results of a preliminary investigation of Toughlove by a Boston College professor, recently presented at the American Psychological Association annual meeting (Klug, 1990 see below). Klug basically concluded that Toughlove works. In 85% of the cases parents reported that their teenager's behavior improved, in 10% it worsened, and in 5% it remained unchanged. It works through assertiveness training and through community support.

In Toughlove parents learn how to use the school, legal, and health system and each other. Toughlove parents are known for putting their children out, but always with support. For example, when Oakes' son returned from treatment he was not allowed to move back into the home. Oakes did support him by putting him into a halfway house and paying for it until his son found a job. "We'll put kids out of our home, but then we make sure they live in another parent's or neighbor's home or have a bed in a shelter." Oakes proceeded to explain why it is important parents take this stand.

When parents join Toughlove they fill out a Crisis Assessment form which details the child's deviant behavior at home, at school and in the legal system. From this Oakes realized that he had become accustomed to, and accepted certain behavior---like stealing, lying, and other behavior which would be totally unacceptable from anyone else. Toughlove's symbol is a fist around a heart and parents are taught that they don't have to accept that kind of behavior from their children.

Oakes then shared the ten basic beliefs of Toughlove:

-Family problems have their roots and support in the culture.
-Parents are people too.
-Parents' material and emotional resources are limited.
-Parents and kids are not equal.
-Blaming keeps people helpless.
-Kids behavior affects parents and parent's behavior affects kids. (Hence they try to get parents to change their behavior.)
-Taking stands precipitates a crisis, but it is a controlled crisis.
-From controlled crises come the potential for positive change.
-Families need to give and get support in their own communities in order to make change.
-The essence of family life is cooperation not togetherness.

Toughlove for Minorities. According to Oakes, Toughlove works and it has the potential to work for everyone. He acknowledged that there is a perception that it is for white, married, middle class and blue collar communities. He countered this by pointing out that in Dayton, Ohio there is an active group organized by a black man and comprised of a large number of blacks from across the economic spectrum. And in Washington, Oakes expected that his group would double in size as a result of a call-in radio program he had participated in recently. He believes that minority participation in Toughlove and similar groups will grow as the these communities become aware that these kinds of problems have no boundaries and neither do the solutions.

Policy Suggestions. Oakes concluded with the following policy suggestions:

-In order to overcome denial parents must receive more training about the signs of drug use.
-Increased treatment methods and facilities should be a major priority for the new "Drug Czar".
-There is a need for treatment programs which have fees based on parents' financial ability to pay.
-There should be some funding support for Toughlove and other family support groups.

Ooms noted at the end of Oakes' talk, that in the substance abuse treatment area parent organizations have not yet received the kind of policy recognition and support that parent organizations have in the health area.

Naomi Karp is the second Vice-President of the Federation of Families for Children's Mental Health, and is presently a partner in Family and Integration Resources. For ten years she managed the children and families program at the National Institute on Disability and Rehabilitation Research. Karp began by explaining that she had both a personal and professional interest in this issue. In 1965 Karp began teaching children with emotional disorders and she saw the need for an organization which could provide support for families of children with various types of mental health problems.

Personal Experience. Then in 1973 her son was born, and she and her family began a personal saga. From one month old onwards her son has experienced repeated hospitalizations and prolonged periods of bedrest for episodes of asthma and bronchitis which frequently develop into pneumonia. Having a child with a chronic illness is very taxing but they learned how to adapt their life style. Fortunately he is very bright so he could make up for the lost school days.

His September allergies came up as he began his Freshman year in high school he but didn't bounce back as usual. He was on quantities of asthma medications and steroids. He was out of school for over a week. Every time the family talked about his going back to school he would get very sweaty, turn red, and start crying. The symptoms of a panic disorder were evident almost every day. They decided to take him to a psychiatrist, who refused to discuss their son's problems with them because it would be a breach of confidence with him.

There was a great deal of other sources of family stress at the time but the psychiatrist was totally unsupportive and advised them to put him in The Psychiatric Institute. This was unacceptable to the parents and to him. So they took him out of school altogether against medical advice and at considerable risk.

Up until this time they had always made the decisions about his medication and medical care for him. But now they realized that he was going through normal adolescence and wanted and needed to start making some of those decisions himself. They got him back into a private school of his choice for the second semester. (He is now doing fine.)

Over the next months Karp and her family received a great deal of help from friends and many professional colleagues and they finally found a very supportive psychiatrist who successfully treated his panic disorder. Karp wondered how other families who did not have these resources would be able to cope. There were no family support groups in the area at the time.

Parent Empowerment: Federation of Families for Children's Mental Health. At the time Karp was a program officer for a research and training center in Portland, funded through CASSP/NIMH and NIDRR in the U.S. Department of Education, which focused on family support in children's mental health. A group from this center came to Washington to present research findings and help in planning an agenda for children's mental health.

One of the outcomes of the conference was a steering committee made up of seventeen parents which met to decide what needed to be done in the area of custody, special ed. services, the lack of coordination of services, and family support. This group met and last year formed what is now the Federation of Families for Children's Mental Health. The elected officers must be parents of a son or daughter with emotional behavior or mental disorders. The organization's philosophy is that children belong in families and there has to be family/professional collaboration for the kids to make any progress.

The Federation intends to address the following policy issues:

---To improve training for mental health professionals, especially in their outreach to minority families, learning not to blame families and to work in partnership with families.

---To promote a study of state laws that require relinquishing custody of a child in order to get mental health services that are too expensive for the family to afford.

---To recommend a blue ribbon commission to study children's mental health issues, particularly hospitalization as first choice of treatment. In 1980-84 children and adolescent hospitalization rates rose by over 350%. "We know that that is insurance driven." Successful community based programs are available and we need to replicate these so there is an alternative to hospitalization as the only choice of treatment.

---To promote national leadership in the area of children's mental health and to promote both service delivery and biomedical research.

Karp concluded by stating that "we need society to destigmatize these mental health problems and stop assuming it is the family's fault. All families have hopes and dreams and visions for their children and it's no different when your child has a mental health or emotional problem. We need to support these children and there are ways to do it that are cheaper than in hospitals."

Points Made During Discussion.

- A Hill staffer asked how best to involve parents in HIV education programs in the schools, she had heard about parents sabotaging such programs? Popper responded that it is important to involve the parents right from the beginning in the initial planning through implementation of the program. You can't just spring a program like this on parents without asking for their input. Karp suggested involving the local and national P.T.A.'s.

- A point was made that there is an assumption that pregnant teens always want an abortion while their parents don't. But often the reverse is true with some parents pushing for an abortion. What about the parent consent issue in this case? Areen mentioned a case on this point in Maryland where a pregnant 15 year old who wanted to keep the baby was being pressured by her mother to have an abortion. The court ruled the girl to be an emancipated minor and she was able to carry through with her pregnancy.

- A question was asked about grandparents' rights. Many times these new grandparents have to put aside their careers when they don't want to in order to take care of their teenager's child. Areen pointed out that this question was getting increasing attention especially in regards to child abuse and neglect cases where the grandparents are often the ones who step forward to take care of the babies. There is one state, Wisconsin, which requires grandparents to financially support the children of a minor.

Oakes mentioned that some grandparents belong to Toughlove, many who may be caring for their addicted child's children, and that there are grandparent support groups.

- A participant told of a time, while living in Virginia, that she had difficulty taking care of her disabled daughter. When seeking help she was told she would have to temporarily relinquish custody in order for her daughter to receive services and she was absolutely appalled at this policy. She asked what sort of policy recommendations could be made in order to change requirements such as those. A panelist responded that there are some Medicaid waiver programs that are beginning to cover services for families caring for someone at home, and many people are working on ways to finance community based care.

- What is the legal and policy situation with regards to school-based clinics and parental notification? Areen noted that on the federal level the Supreme Court has deferred decision-making responsibility to the states. Ooms added that most school based clinics ask for parental consent in some way. Though not legally required to do so, they do it to protect themselves. Ooms cited a useful document by the Adolescent Health Project at the Youth Law Center, which details the legal and policy status of school based clinics (English and Tereszkiewicz, 1988).

Areen explained that the laws she reviewed earlier providing for adolescents own consent on certain issues are permissive, rather than mandatory. They do not stop a particular clinic or hospital from deciding it wants to require parental consent or notification.

- Ooms then asked about the legal situation in mental health, especially substance abuse. State laws generally say that adolescents can receive substance abuse treatment without parental consent. This hasn't stirred up a lot of controversy, perhaps because not many teens voluntarily seek treatment. Oakes stated that he did not know of any cases where the teen had sought treatment voluntarily, most of the time it is the parents who are trying to get the child into treatment. There is also the issue of who pays for treatment.

Ooms proposed that perhaps this law was meant to allow teens the opportunity to speak freely with school counselors about their drug use without fear of it getting back to their parents. It was pointed out that the same held true for private physicians.

Ooms added that payment for confidential treatment to a teenager is a very difficult issue. Although, for low income families, if a child knows the family Medicaid number then the teenager may receive confidential treatment.

****Additional References:**

Klug, Wayne, *A Preliminary Investigation of Toughlove: Assertiveness and Support in a Parents' Self-Help Group*. Presented at the American Psychological Association Annual Convention, August 1990. Available from the Psychology Department, Boston College, Chestnut Hill, Massachusetts 02167.

Ooms, T., Herendeen, L., *Implementation of P.L. 99-457: Parent/Professional Partnership in Early Intervention*. Background briefing report prepared for the seminar held in Washington, DC on June 8, 1990. Available from the Family Impact Seminar.

PARENTS' ROLE IN TEENAGE HEALTH PROBLEMS:

ALLIES OR ADVERSARIES?

Background Briefing Report

INTRODUCTION

Confusion, ambiguity, inconsistency and controversy are the current hallmarks of the law and practice with respect to what role parents should play in their adolescents' health care. Parents are understandably bewildered by the situation. In most communities, for example, their written permission is required before the school nurse will give their 17 year old daughter aspirin for a headache or before the emergency room doctor will stitch up a cut on their 16 year old son's head. Yet the daughter may get an abortion and the son receive drug abuse counseling without the parents even being told about the pregnancy or drug problem. Health care professionals are similarly uncertain about when they must consult teenagers' parents before they can provide them services.

Until recently the common law rule was that consent of the parent was necessary to authorize any medical treatment of a minor. But over the past two decades most states have enacted laws that expand minors' rights to consent to their own medical care especially in certain circumstances such as emancipation and maturity and for specially sensitive issues such as treatment related to sexual behavior, mental health and substance abuse.

The public debates about this issue have largely centered on the difficult dilemmas of parent/teen confidentiality and consent in teenage pregnancy. Regrettably, this focus has resulted in serious neglect of many other critical aspects of the parents' role in their teenagers' health. In the numerous recent research publications, conference reports and meetings on the subject of adolescent health and treatment, parents are seldom mentioned. It is as if, once a child reaches the age of sexual maturity, parents are viewed as either irrelevant or potentially harmful to their teenager's health overall.

Unfortunately the policy and practice paradigms have evolved largely in response to the teen/parent conflicts that can arise over teenager's sexual activity or pregnancy. It is these paradigms that appear to dominate the whole field. As a result, in policy discussions and debates teenagers' parents are primarily viewed as potential adversaries. Proposals to require their involvement are regarded as creating unnecessary barriers to teenager's receiving needed health care services. This view of the parent's role is clearly at odds with most everyday family experience.

The facts are that on a daily basis parents, and other family members, play a very important role in promoting their adolescents' health, preventing injury, accident and disease, helping them cope with disability and recover from illness. In general health care professionals agree that parents must be closely involved in sick adolescents' medical or psychosocial treatment for it to be effective. This is true especially when a teenager is abusing alcohol and/or other drugs, has a serious emotional and behavioral disorder or a chronic physical illness or disability. This view is echoed even more strongly by individual parents and parent organizations formed to advocate for greater recognition of their role and improved collaboration between themselves and health care

professionals. The parents view is that they are essential allies, not adversaries, for effective adolescent health care: allies of their adolescents and allies of the health care providers.

Given the degree of public concern about the current high rates of adolescent mortality and morbidity, the failure to study, discuss and address the varied and important roles and resources that parents have to offer is to be deplored.

The special challenges of adolescent treatment.
(Sources: Fletcher, *et.al.*, 1986; Holder, 1984, 1988; Gittler, *et.al.* 1990; Morrissey *et.al.* 1986; Patterson, forthcoming.)

Nevertheless the stage of adolescence does pose several very delicate and difficult challenges for health care providers, policymakers, parents and teenagers themselves. Adolescents must gradually assume increasing responsibility for themselves, and learn to make independent, autonomous decisions. Parents must learn to relinquish control, while continuing to give firm guidance, advice and economic and psychological support. This process of renegotiation is gradual, unsteady and may take some false turns. From time to time, and in a few families much of the time, this process engenders serious disagreement and conflict.

It is difficult for health care professionals to know how to support adolescent's successful transition to adulthood. When there is a real, or apparent, conflict of interest between the parent and teenager, they are placed in a very difficult situation requiring sensitive professional skills and judgements. The natural temptation is to side with either the teenager or the parent. Yet most agree that what is needed is a very careful, case by case, balancing and mediation of the interests and views of parents, teenagers, health care professionals and sometimes the state i.e. the public. The law is, inevitably, a very blunt and awkward instrument to accomplish these ends.

This briefing report will attempt to clarify the various dimensions of this complex issue through synthesizing the key points emerging in the research and professional literature. We also report on parents' own views and actions as they are increasingly being expressed collectively through parent self-help organizations. The key questions we address are:

- What is the current legal status of the parent-teen relationship in health care with respect to notification, consent, confidentiality and financial responsibility?

- What does research, professional experience and parents themselves believe is, ideally, the parents' role in promoting teenagers' health and obtaining treatment for health problems? How does this evolve as the adolescent gets older?

- What are the special issues and dilemmas of the parent-teen relationship with respect to the challenges involved in acute and chronic physical illness, substance abuse and emotional and behavioral disorders?

- What explains the growth of so many new parent organizations in the health field and what contribution are they making?

- How can policymakers best help parents fulfil their role as the key promoters and guardians of their adolescents' health and well-being? How should policymakers respond to situations of parent-teen conflict around these health problems?

THE LEGAL FRAMEWORK

(Sources: Alan Guttmacher Institute, 1981; English & Tereszkiewicz, 1988; Fischer & Sorenson, 1990; Gittler, Quigley-Rick & Saks, 1990; Hafen, 1976; Holder, 1984 & 1988; Morrissey, Hofmann & Thrope, 1986; Mosbacker, 1986; NOW, 1990; Ooms, 1981; Wardle, 1988; Worthington, 1988 a and b.)

The basic common law doctrine is that parent consent is necessary for any medical treatment of a minor child, that is, age 17 and under. (Since the early seventies, the age of majority has been lowered so that it now stands at 18 years in forty seven states and 19 in three states, Alabama, Nebraska and Wyoming.) The physician who does not obtain parent's informed consent is therefore technically liable to civil prosecution for "assault and battery" although in the few occasions when such actions have been filed they have not generally been successful. In most instances the consent of only one parent is sufficient. In the case of divorced, or separated parents, it would normally be the custodial parent who needs to give consent unless their divorce agreement states otherwise.

Legal tradition has long supported the basic concept of family autonomy and parental authority which is generally interpreted as minimal interference with parental decision making and choices. However, over the past century and a half, parents' rights have been considerably narrowed through compulsory education and child labor laws and child abuse and neglect statutes. Nevertheless in the sixties and seventies, in a series of Supreme Court decisions, constitutional protection of family autonomy and privacy was strongly reaffirmed as being fundamental, but these rights were not declared absolute.

Additional principles cited in the literature that underlie this general doctrine of parental consent for minors' medical treatment include:

---Minors have traditionally been deemed legally incompetent to give informed consent, just as they have not been legally permitted to enter into binding contracts.

---Parents are presumed to act in their children's' best interests.

---Parents' financial liability for the costs of medical treatment provided to their children require that they consent to the treatment. Health care providers, and the public, have an interest in assuring they will be paid for services provided.

Much less commonly cited in the legal literature, but uppermost in the minds of many health care professionals, parents and political conservatives, are three additional reasons:

---If the parents' consent is not obtained, and they have no knowledge of the treatment provided, the treatment may be less effective. (The minor may not know the relevant details of their own or their family's medical history; the parent will not be in a position to encourage compliance with the prescribed medical regimen etc.)

---The treatment may result in unanticipated, undesirable medical or other consequences which the parents have to respond to and are financially liable for (e.g. the parents may end up paying for the costs of their daughter's pregnancy and financial support of her child; infection or other problems may follow upon an abortion).

---The condition for which treatment is sought may be closely connected with other areas of the teenager's life which the parent is legally or financially responsible for (e.g. the substance abuse may help explain the child's frequent school absences or recent car accident).

Minors' rights to consent

Since the late sixties, several exceptions to the common law doctrine have been established through state statutes and Supreme Court rulings. The children's rights movement together with an increasing body of research and clinical experience on adolescent development has successfully challenged several of the assumptions that undergirded the common law doctrine.

First, many no longer believe that parents' can be trusted to act in their minor child's best interest. Instances of serious parent /teen conflict, parental abuse and neglect, and alienated youth who runaway from home and so forth have impressed professionals and led them to question the benefits of the parental consent presumption. In such cases most health care professionals sympathies have tended to lean towards the adolescent who is often seen to be in need of protection from parental authority, abuse and anger that may follow upon their learning about their teenager's request for abortion, contraceptives, or substance abuse or mental health services. Through their national associations, health care professionals vigorously asserted that parental consent was a major barrier to adolescents obtaining needed treatment for sexuality related care, substance abuse treatment and mental health treatment and must be removed. They believed that parental involvement was desirable but only with the voluntary cooperation of the adolescent. Their views were supported by many in the civil rights movement who were advocating for children's rights in other areas as well as health.

There is some survey research that supports the alleged barrier effect for sexuality related services for teens: enactment of parental consent and notification laws have been followed in some communities by an increase in teen pregnancy rates and teen abortions being obtained at later stages, which are therefore more dangerous to health (see Gittler p. 22). There are no reports in the literature of studies that examine the barrier effect of parental consent for substance abuse and mental health services.

Second, the presumption of minor's legal incompetence was challenged as not resting on any empirical basis. As the concept of informed decision making became fleshed out, many studies suggested that many adolescents were quite competent and sufficiently "mature" to be able to make informed decisions on particular medical care issues. (For a summary of this research see Gittler et al. Part II and Appendix A.) Some scholars disagree with this conclusion (see Worthington, 1988).

These were the major challenges that led to a number of exceptions to the basic parental consent presumption being established by state statutes. In addition the interest s of public health in containing the spread of contagious, venereal diseases, were considered paramount in recommending easier access of teens to sexuality-related health care. These exceptions related to the special characteristics or circumstances of selected groups of minors or to specific types of health problems or services.

State variation and inconsistency. State laws vary considerably, and keep changing, with respect to which specific parent consent exceptions are mentioned in their statutes and what restrictions are placed on the exceptions. (A few states have established a broad presumption that adolescents may consent to all types of medical treatment.) Since the statutes have been added in an ad hoc, patchwork, fashion at different times for different health problems there is often considerable inconsistency of consent policies within the state. We list here the general categories of exceptions that large numbers of states have already established. (Those interested in specific consent laws currently in effect in each state should consult Alan Guttmacher Institute, 1990; Gittler *et al* 1990, and Morrissey *et.al* 1986.)

Categories of Parent Consent Exceptions

Increasingly in most states laws now provide that adolescents may consent to their own treatment in the following situations:

---When they are found to be "emancipated" or "independent" i.e. are married; have a minor child; are serving in the armed forces; or living independently and economically self-supporting.

---When they are found by the court, or a health care professional, to be sufficiently "mature" to provide informed consent.

---In emergency situations.

---When they seek services related to family planning, venereal disease, pregnancy care and childbirth

The issue of abortion is more complicated. The basic right to abortion was established by the Supreme Court in 1973 with the Roe v. Wade decision, and elaborated upon and qualified in several decisions since. The Missouri v. Danforth decision in 1976 affirmed that minor's have the right to give their own consent for abortion. Many states have laws which require parental consent and/ or notification for minors' abortion, although many of these have been enjoined by the courts or are not enforced (see Alan Guttmacher Institute, 1990). A series of Supreme Court rulings, the most recent in 1990, essentially affirmed minors' basic right to abortion but upheld the constitutionality of state parent consent and notification laws if the state statutes also provided an alternative procedure---such as a judicial by-pass procedure--whereby "a pregnant minor could demonstrate that she is sufficiently mature to make the decision herself, or,that despite her immaturity, an abortion would be in the minor's best interests" (Morrissey, *et. al.* p.68). These alternatives which thus permit minor's access to abortion without parental consent.must the Court said be timely and not unduly burdensome.

Additional exceptions to the parent consent presumption that many states have enacted are:

---Drug and alcohol abuse treatment (only five states and D.C. do not have such statutes).

---Mental health treatment. In almost half the states minors may consent to their own outpatient treatment. However, in about two-thirds of the states parents are able to make a voluntary commitment of their child to a mental hospital (inpatient service) over the minor's objection although the minor does have some, albeit minimal, constitutional due process protections in these cases. One half of the states allow minors to voluntarily admit themselves to psychiatric inpatient units, but this is a rare occurrence largely for financial reasons, since teenagers seldom have the resources to pay for such treatment.

It may not be well understood that although state law may allow, in the above situations, the adolescent to consent to treatment without his/her parents consent, or over the parents objection, this does not oblige the medical provider to provide treatment under this condition. Health care professionals, clinics and hospitals are generally free to impose their own parent consent provisions if they wish as a matter of institutional policy as indeed many do especially with regard to alcohol, drug abuse and mental health treatment but also in reproductive care. For example, a survey of private physicians in 1984 reported that one in four would not provide contraceptives to minors without parental consent (Forrest 1988, p.90).

Some federal laws do impose restrictions on professionals providing services with federal funds for example the Title X family planning program requires that contraceptives be provided to minors without parent consent. On the other hand the Adolescent Family Life Demonstration program requires parent consent for all pregnancy related and teen parent services. However it is unclear what degree of compliance there is with these provisions.

School Based Clinics. There is a great deal of interest in, and controversy about, the growing number of school-based clinics---around 120 school-based clinics, in 61 communities in 30 states providing---which provide a variety of preventive health services to adolescents on, or near the school (English and Tereszkiewicz, 1988). These clinics are funded from a variety of sources and are mostly located in low income communities. Contrary to the public impression, only 15% of these clinics actually dispense birth control.

All school based clinics require some form of parental consent. The specific form and scope of the consent varies considerably with each school. Some of the forms simply list the variety of services available and the parent's signature implies the student may receive any of the services. Other forms require parents to specifically check which services the parent permits the teenager to receive. In spite of these consent procedures it seems clear that in most communities the state law would allow schools to provide some of these services without parental consent. These procedures have been criticized on various grounds by conservatives and others as not sufficiently providing for parent involvement or follow up if certain medical conditions are diagnosed.

Notification and Confidentiality.

Confidentiality. Patient-physician confidentiality is protected by law and by health care professionals' own codes of ethics. In most other health-related professions---such as nurses, psychologists, social workers, family therapists and counselors---professional ethics also requires their respecting patient confidentiality although in only a few jurisdictions are non-physicians' communications given legal protection.

The principle of confidentiality is generally considered to apply to adolescent health care although there is little statutory or case law on this issue. (A federal regulation does govern the confidentiality of information and records in federally assisted drug and alcohol programs.) There are some exceptions to this presumption, for example in situations of suspected abuse or neglect when there is an obligation upon the professional to report this suspicion to the public child welfare authorities. Further, since the Tarasoff court decision in California in 1976, it is generally agreed that whenever the professional believes the adolescent's (or adult's) behavior or condition poses a serious threat to him/herself or others the health care provider has a "duty to warn" the parents or other authorities as appropriate.

In practice, health care professionals interpret the confidentiality code in very different ways. Some for example, believe that the disclosure of a teenager's serious drug or alcohol abuse, or a positive result of a test for the AIDS virus, would fit into the category of serious harm and that they thus have a duty to breach patient confidentiality. Others would disagree.

Some health care providers treating adolescents routinely provide little or no information to the family even when the parents know that treatment is being given. On the other hand family-oriented physicians, nurses, and social workers and family therapists will usually be very careful to discuss early on with both parents and adolescents what type of information they believe it will be important to share and what they will keep confidential. Generally they try promote intra-family communication about important health problems.

Confidentiality of adolescents' medical records can create some difficult dilemmas however, especially with respect to school health and counseling records. For example the Family Educational Rights and Privacy Act in 1974 gives parents, but not students under age 18, the right to access their child's public school record (but not the private notes of school counseling personnel). These records may contain information of a sensitive nature, regarding referrals to the drug counselor, or the results of psychological tests which would normally be considered confidential and not accessible to parents but which may be revealed under this law if the parent seeks to inspect the record.

Parent Notification. The question of whether parents should be notified, over the adolescent's objection, of their minor child's receipt of certain types of health services (for which parent consent is not required) has become a much debated issue. Parent notification is the subject of widespread and continuing public controversy especially with relationship to contraceptive and abortion services and many bills addressing this issue are being introduced into state legislatures (see Alan Guttmacher Institute, 1990). The federal regulation issued in 1983, requiring notification of prescription contraceptives provided to minors in a federal program was struck down by the courts.

On the other hand in June 1990, the Supreme Court ruled in an opinion on a Minnesota case, Hodgson v. Minnesota, that while states may not impose a blanket two-parent notification requirement on minors seeking abortions, as long as there is a judicial bypass provision for minors who do not want to tell both or either parent, then the law was constitutional. There is a great deal of variation between the states in terms of notification requirements when parent consent is not required. Some of the state statutes do require notification, others simply permit it, and others don't mention the issue.

While policymakers tend to make a distinction between notification and consent laws, believing that notification statutes are less onerous, teenagers themselves, and many health care professionals do not see a significant distinction. Some believe that teenagers' main concern is to prevent their parents' knowledge about their sexual activity, not so much whether or not they will refuse consent to the contraceptives or abortion. Moreover it is said that parents, once they know about the pregnancy, are clearly in a position to exert undue pressure which will , in effect, force a teenager to carry her baby to term. (Equally of course, this pressure may be applied in the direction of "forcing" her to have an abortion.)

Some proponents of notification suggest that if the parent were notified of the results of a positive pregnancy test, rather than waiting until the teen has decided on an abortion, that there then is a substantial difference between notification and consent. Notification in this case allows parents to have some input early on in helping their adolescent make a decision about her pregnancy rather than simply being in a position to veto her wish to have an abortion. Some of them point out that there is very little evidence of what the results would be of parent notification of a positive pregnancy test , some parents might advise an abortion, others might hope she would bring the pregnancy to term. .

With respect to a minor's request for abortion the following additional arguments are made by proponents of notification:

---When parents are not notified neither the teenager nor the physician nor the judge has direct evidence of what their reactions will be to the pregnancy. Once the initial shock has worn off, her parents' actual reactions are likely to be much more supportive than she fears. Teenager's in such a crisis are in need of support from those closest to her. Carrying around the burden of her "secret" abortion may exacerbate her current difficulties with her family, and cause worse problems when it is revealed later on.

---With notification parents have a chance to help the teenager make a decision, and since they know her better than the physician, pregnancy counselor, or a judge in a by-pass procedure, the decision is likely to be a better one for her as a result.

Payment for medical services to minors

In the real world, financial considerations probably have more influence over medical practice than notification and consent laws for the vast majority of teenagers who receive care in the private sector. When parents consent to medical care they are clearly legally responsible for paying the costs of that care. But when the care is provided without the parents' consent or knowledge the parents are generally relieved of this financial liability. The adolescent is then usually considered liable, this is especially the case if they are emancipated, or have qualified for their own public benefits. In practice, when confidential care is provided, adolescents own financial resources are often evaluated on a sliding fee scale. Since their income is often seriously limited, confidential treatment services are heavily subsidized or provided free.

Minors whose families receive Medicaid may be able to secure payment on a confidential basis if they have knowledge of the Medicaid number. But this is only true in those jurisdictions which do not send the family a copy of an itemized claim form which some are beginning to do in order to prevent fraudulent claims.

Families' private health care insurance plans are not generally a source of payment for adolescent confidential care; prepaid health plans---such as provided by health maintenance organizations---sometimes are.

Other legal issues

There are several other special situations that need brief mention. In general federal regulations do not permit minors to serve as research subjects without parental permission though there are a few exceptions when there is minimal risk involved. Minor's may consent to their own medical treatment when the parents refuse to do so and the court makes a finding of parental medical neglect, for example for a blood transfusion or surgery. Parents' consent is generally required for a minor to donate blood. Court authorization is generally required for minors to donate organs but thus far courts have issued very conflicting opinions about whether minors may donate their organs even with parental permission.

DIFFICULT CLINICAL DILEMMAS.

The following case examples are a selection of several compiled by an adolescent medicine specialist, Dr. S. Shonberg, and were cited in a recent publication to illustrate the fact that neither the law, nor existing professional ethical standards, provide clear guidance to health care professionals when faced with many of the real life dilemmas involved in providing health care to adolescents (see Gittler *et. al.* p. 139-140).

- A 16 year old boy is discovered to have a malignant tumor of the bone. Appropriate treatment requires amputation of his leg. His parents consent to the surgery but he refuses. He will accept all other forms of treatment but would "rather die with both legs than survive as a cripple!" Do you operate without the consent of the boy? Do you seek a court order against his wishes?

- A 17 year old boy is admitted to the Intensive Care Unit with multiple fractures and disorientation. He was the driver of an automobile involved in a collision in which three passengers were killed. As part of the evaluation of his state of consciousness you determine that his blood alcohol level is well above the legal limits for intoxication. Do you share this information with his family in explanation for his confusion? Do you share it with the authorities who are investigating this fatal accident?

- A 16 year old girl is brought to care by her mother who is concerned about poor school performance and disruptive behavior. In your private interview with the girl she confides that she is smoking marijuana a few nights each week.....she insists that this information about her drug use not be shared with her mother. Do you tell the mother anyway? What if the mother specifically asks, "Is my daughter using drugs?".....

- A 15 year old girl returns with her parents to discuss her recently diagnosed pregnancy. Her parents are certain that the only acceptable course of action is to terminate the pregnancy. The girl is adamant in her refusal to consider abortion. What do you do?

- You are caring for a 17 year old who has AIDS secondary to a transfusion. His 16 year old girl friend is aware of the diagnosis but they continue to have unprotected intercourse. She "doesn't care", she "loves him." Do you inform her parents?

PARENTS' ROLES IN ADOLESCENT HEALTH AND MEDICAL TREATMENT

(Sources: Baumrind, 1987; Campbell, 1986; Doherty & Campbell, 1988; Litman, 1974; O.T.A. forthcoming; Pratt, 1976; Wright & Leahy, 1987)

Parents' roles in adolescent health

Note: In this section of the report we discuss the part that parents play in the health of their own teenage children. In the section on the parent movement (see page 14) we discuss the influence of parents, organized collectively, at two other levels (i) at the community level in providing assistance and support for other parents, and (ii) at state and national levels where parents are making valuable contributions to policy and program planning, development and monitoring.

The family's influence on child and adolescent health is clearly very important. Parents are the primary promoters of good health, and the major providers of preventive health care and treatment. (In this discussion the term parents are used as a shorthand for any person in family who fulfils the major parental role in the teenager's life---it may be a grandparent, step parent, older sibling or uncle.) Research and clinical experience has identified many avenues through which this influence is transmitted although there have been very few studies that have specifically examined the pathways through which parents' effect on adolescent health specifically.

It is important for health care providers to realize that typically adolescents themselves are reluctant to openly admit that they are still dependent upon their parents in these ways, may resent or ignore their advice and help and may deny, when they are sick, their need for parental support. But these protestations do not change the facts. The principal ways in which parents can influence their own adolescents' health status, whether positively or negatively, are through:

---Genetics (certain diseases such as alcoholism, diabetics, depression have a genetic component);

---Parent education and modelling (with respect to nutrition and exercise, home and vehicle safety, basic preventive care, risk avoidance and general life style).

---The family's socio-economic environment (parent's income is clearly associated with access to health care. Studies have found however that parental education is even more positively related to health status than income.)

---Parents' ability to communicate, show interest, love and provide emotional support to their adolescent.

---Parents' setting behavioral rules, expectations and limits (for example with respect to curfews, chores, bedtimes, use of car).

--- Family's transmission of stress such as engendered by death, divorce, serious illness or family conflict. (Many illnesses, and even viral infections, may be triggered or made worse by unresolved stress in the family.)

---Parents' responding promptly to signs of illness and either encouraging the teenager to seek treatment when appropriate or to employ home, self-care remedies when not.

---Parents searching out the range of options of medical treatment and services available which they can afford.

---Parents helping adolescents to coordinate and negotiate their way through the mazes of the health care system.

---Parents asserting their rights to visit and stay with the adolescent when hospitalized for accident, surgery or illness.

---Parents acting to reinforce treatment goals, monitor compliance and provide home nursing and protective care to the sick or disabled teen.

---Parents helping the adolescent assume increasing responsibility for health care decisions and learning to cooperate with health care professionals.

Research findings on the family's impact on health.

While all these different roles and avenues have been identified in the published literature, there is very little research that elaborates on how effectively these roles are performed by different families in different situations and circumstances. (Office of Technology Assessment, forthcoming.)

Views on the nature of adolescent and family development have undergone radical transformation. Earlier research and writing about adolescence described the central task of adolescence as being to become detached and independent of, in effect "emancipated" from, parents. Recent research has led to a reconceptualization of the developmental tasks of the adolescent stage of the family life cycle.

Adolescents need to learn to assume increasing responsibility and decision making but within the context of their close relationships, not away from them. They must renegotiate their relationship with their parents so that they can assume greater autonomy, but they also need to remain connected with their parents in a new relationship of mutuality and friendship rather than dominance and control. Parents need to gradually "let go", but stay interested in their children, and provide them with continued advice and support. There is a developing consensus among investigators that those teenagers who remain engaged with, rather than independent from, their parents during their early adolescence are less susceptible to peer pressure.

There is some research however that provides insights into those family characteristics and processes that facilitate the achievement of these goals and are associated with better health outcomes.

Baumrind's research specifically focussed on the characteristics and patterns of families with an adolescent. (Baumrind, 1987; OTA, forthcoming.) She identified several protypical models of family relationships:

--**traditional families** which value cultural continuity and accept the child raising patterns and value beliefs of previous generations. Their children often develop considerable self-discipline and are likely to internalize these values.

-**authoritarian /restrictive families** are characterized by paternalistic, rigid and domineering styles of child raising;

-**permissive, overindulgent, lenient** families in which parents make few demands on their children, have low expectations and set few limits but are warmly, closely attached to them.

-**indifferent, inaccessible, lenient** families in which parents are very uninvolved, make few demands and care little about what the teenager does or how he or she feels.

-**authoritative** families in which parents are more demanding than permissive parents, but more flexible and democratic than the authoritarian parents and more emotionally warm and supportive than indifferent parents. Authoritative parents are willing to clearly state their values and expectations and set limits for their children, but they keep open the lines of communication and are prepared to negotiate and work towards the adolescent developing increasing autonomy.

In her ongoing research Baumrind has found that teenagers from homes with authoritative parents are consistently more socially competent, have better mental health and are less likely to abuse drugs than their counterparts growing up in other types of families. But traditional families are more successful at shielding their teenagers from risk-taking behavior, less because of their values and more on account of their strong mutual attachments that persist through adolescence, and their apparently coherent, consistent management policies (Baumrind, 1987, pp.113-114).

Family systems research has identified and developed measurement scales of three critical dimensions of family functioning which echo Baumrind's findings (Olson *et al.*, 1979). These dimensions are:

--family **adaptability**, its ability to accommodate change;
--the degree of closeness, that is **cohesion** (from enmeshed to disengaged) among family members;
--the quality of family **communication.**

On each of these scales, families which fall at either extreme are more likely to experience mental health problems and delinquency than families which fall more in the moderate range.

Parents' roles in treatment of specific health problems

In this section we review selected difficulties, dilemmas and needs facing parents whose teenagers need treatment in three broad categories of illness---chronic physical illness and disability, substance abuse, and mental, emotional and behavioral problems. These categories are rather arbitrary and typically overlap: a seriously diabetic teenager may have problems of drug abuse, a teenager with cancer may be seriously depressed and so forth.

Chronic physical illness and disability. A child's chronic physical illness and disability places extraordinary, continuous sets of extra demands, stresses and challenges on all members of the family, especially the primary caregiver, who is usually the mother. Although there are major commonalities in the experience of families with a disabled or chronically ill child, each illness or disability also imposes some unique demands and challenges.

The response of the family to these impacts can, in turn, reciprocally influence the health, adjustment and well-being of the chronically ill child. Some families seem to become weaker and have more difficulties coping as a result, others become stronger and more resilient (Patterson, 1990). Families with a seriously disabled or ill child need a strong supportive network of friends and neighbors, considerable practical assistance and occasional respite care to provide relief from the continuing demands of care. Parent support groups can be an extremely valuable source of help (see p.14).

In families caring for seriously disabled youngsters the task of managing the transition to adulthood presents some special difficulties. Due to their illness or disability these young people are extraordinarily dependent upon their parents and others, and often upon medical technology, to manage the tasks of everyday life. Yet this continued dependence battles with their biological and psychological drives for increased autonomy.

Until recently it was assumed that the major developmental task of these parents should be to help the disabled young person learn self care and to become independent of the need for physical assistance, especially from family members. However, although some progress towards these goals can be made, complete independence is often an unrealistic goal. The teenager has to come to terms with his or her continued dependence upon others for physical assistance. Yet unless the teenager is severely mentally or emotionally disabled, he or she can be helped to become more autonomous in terms of decision making, choices and accepting responsibility for his or/her own actions (Crittenden, 1990).

The parents must gradually learn to assume a less protective role, but they still need to be careful to monitor these adjustments and not move too fast in the direction of greater independence. As with healthy teenagers, their task is to help their teenager make the transition not from dependence to independence but from dependence to interdependence. Those families which are flexible and in which there is open communication may find it easier than others to carry out the necessary renegotiation of family roles and behavior.

The legal and ethical issues of confidentiality and consent become more acute in this situation. On the one hand since the parent has to be so much more involved in the treatment, the issues of confidentiality and consent often seem moot. Nevertheless the disabled teen must be included in information sharing and decision making and many times will need to have the final say.

These issues can become even more complicated once a disabled teen reaches the age of legal majority. His or her substantial caretaking needs and dependency continue, and yet, if the

adolescent remains living at home, the parents will still have daily responsibility for their care and yet they have no legal rights to information or to be involved in the decision making unless they are appointed guardian---which is usually only done in cases of legal "incompetence."

Adolescent Substance Abuse. The large majority of adolescents experiment with alcohol and drugs. Some researchers suggest that a certain amount of risktaking is to be accepted as part of the normal development at this stage and is not a sign of pathology (Baumrind, 1987). But for those adolescents who go on to become regular users, and hence abusers, family factors can clearly play an important role in the development and/or maintenance of the patterns of abuse. Genetic predisposition, a history of alcohol or drug abuse in the family or current familial abuse, high levels of family conflict, poor communication, stressful events, or simply the parents' inability to provide authoritative limits on their youngster and renegotiate their relationship---all these factors may play a part in the teenager's drinking or drug abuse. Parents also point to the negative influence of community cultural factors, transmitted through the media and other community institutions, which provide, sanction and even encourage easy access to alcohol and drugs.

Typically both the teenager and his parents will deny the existence of a substance abuse problem or how serious it is and may delay seeking treatment till the consequences of not doing so become severe. Alcohol and drug treatment programs do not generally treat adolescents for more than a few outpatient visits without parent consent largely because they do not believe treatment can be effective without some level of parent/ family involvement. Parent involvement is considered necessary in order to promote and sustain the adolescent's recovery and alter their own patterns of behavior which may have unwittingly sustained, or "enabled" the abuse. Programs involve parents in a variety of ways in the teenager's treatment. They may receive therapy or counseling for themselves, together with their teenager or in groups with other parents.

Self-help groups for the parents---such as Al-Anon and Toughlove---often provide critical emotional support and practical assistance to parents who can become quite distraught and "dysfunctional" as a result of dealing with an "out-of-control" teenager. For some families, who have not found professionals to meet their needs adequately, these groups are alternative sources of help and support. For other families, self-help groups are seen as a distinctive and valuable and essential adjunct to professional treatment.

Counselors who work with adolescents in school or community agencies appreciate the need for assuring their clients of confidentiality. Yet when they become aware of the adolescents' drug abuse but believe that they are bound to respect the student's confidentiality they may feel their hands are tied and do not share this knowledge with the parents. Parents in turn, may be very angry when they only find out after their daughter is arrested by police on a drug charge, that the school counselor has known about their daughter's drug abuse for two years.

It is rare for a teenager to seek intensive treatment on their own and thus the state laws permitting minors consent seldom need to be invoked. More often it is the parents, once alerted by others, who try to insist on treatment. Many schools now have student assistance programs, focusing specifically on youth's alcohol and drug problems. It is their general practice to inform the parents and work with them to get their youngster into treatment. Frequently this notification to parents is met with denial and outright hostility.

Mental Health Disorders. The emotional, mental and behavioral problems for which teenagers may receive mental health services range from quite minor, transient behavior problems to major, chronic and extremely disabling conditions such as schizophrenia, severe depression and so forth. Parents of seriously emotionally disturbed adolescents face some special anxieties: while these teenagers are not as physically dependent upon their parents as the physically ill or

handicapped, parents are aware that their judgment in potentially harmful risk taking and social situations may be very poor. Thus it is equally difficult for these parents to encourage their adolescent's autonomy and increasing responsibility. In addition to their basic concern about the cost and availability of treatment there are a number of issues and questions that these parents face.

---Is the type of treatment available, and offered, appropriate for the degree and type of problem the teenager is experiencing? This is a serious public policy issue as well since there is considerable evidence that adolescents who are simply "out of control" are being unnecessarily hospitalized in increasing numbers in private psychiatric hospitals (Weithorn, 1988). There are several factors, including the easy availability of insurance, that appear to explain this development, but one of them is the dearth of services in the community which give practical help and assistance to parents with seriously troubled, acting out, but not psychiatrically ill, youngsters. (There is also a dearth of community based services for child and adolescents who are seriously emotionally disturbed.)

A related but very different problem is that many parents of very seriously disturbed teenagers, who clearly need expensive treatment ---such as residential care---which the parent cannot pay for, are advised they need to relinquish legal custody of teenager for the sole purpose of obtaining these services at public expense (McManus and Freisen, 1989).

---To what extent will they, the parents, be involved in the treatment or told about their teenager's problems? As mentioned above, mental health professionals treating adolescents vary a great deal in what they communicate to parents, in the way they work with them and how effectively they do so. Some in their well meaning efforts to explore possible "causes" of the adolescent's emotional problems in family history and current functioning, too often make parents feel even more guilty and to blame for their child's difficulties. These feelings are not usually constructive to the treatment process nor do they facilitate change. Others, including most family therapists, are more oriented to searching for family strengths and ways to help parents gain confidence and feel empowered to meet their troubled teenager's needs.

THE CONTRIBUTION OF THE PARENT MOVEMENT.

(Sources: Pizzo, 1983; Turnbull and Turnbull, 1978; Westin, 1981; York and York, 1982 & 1984).

Parent activism in children's health care is growing in strength, numbers and effectiveness. It is reaching out to include parents of children with types of health problems which have not previously been represented. Parent health care related groups are springing up in hundreds of communities all over the nation. These groups are banding together as organizations in state and national federations. Although originally a white middle class, suburban phenomenon, these parent organizations are beginning, slowly, to reach out more successfully to low income and minority families.

Roots of parent activism. The earliest parent organizations evolved in the sixties in response to the neglected service needs of retarded children. They were extremely effective in focusing policymakers attention on their situation. Parents were in the forefront of establishing the rights of handicapped children to public education and were closely involved in the development of landmark special education laws at state and federal levels. Since then parent organizations have grown up to respond to the needs of families of hospitalized children, children with chronic illness and disability, children with autism, with terminal illness, to prevent teenage substance abuse, to prevent drunk driving, to assert parents rights in their children education, to help parents of young substance abusers, to help parents who have abused their children, to help bereaved parents, to assist parents of adopted children and others. (For examples see p. 21.)

What lies behind the growth of this parent activism? Parents join together for many compelling reasons: Their shared experience of living with a child with special needs; their shared frustrations at the inadequacy of services for their children; and by their shared anger at the way that they, the parents, are so often treated by the helping professions. Parents grew tired of being blamed for things that are far beyond their control. In addition parents of out-of-control and substance abusing teenagers are often angry and frustrated by the way that many aspects of their community and societal environment feed into teenagers' destructive behavior and undermine parental authority.

The parent organizations generally engage in both self-help activities and advocacy. Self-help activities include filling in the gaps in practical services, and meeting each others needs through group support and education at regular meetings. Community and political advocacy efforts focus on improving the quality or availability or services and changing professionals' attitudes about parents' needs, capabilities and resources. With a couple of exceptions these parent organizations do not focus specifically on the health problems and needs of adolescents but of children and youth generally, but many of them are now articulating some of the special issues of caring for a disabled, sick or troubled teenager. (Unfortunately parent leaders are so busy that they have written little on the subject.)

Typically parent organizations survive and flourish supported solely through volunteer time, skills, expertise and donations. Gradually, some of the older organizations in certain fields are beginning to get government funding for special projects which provides them with some financial stability. This primary or exclusive reliance on volunteer help accounts in large part, many believe, for the reason why parent self-help organizations have made fewer inroads into low income neighborhoods and communities.

Goals and activities.

Mutual help. A primary goal of these parent organizations is to provide the kinds of assistance to each other which only another parent, who has shared a similar experience, can provide. This includes listening with empathy, being non-blaming and non-judgmental and sharing information about coping strategies and resources. These support groups break down the isolation and loneliness that too often is the lot of parents with a severely ill, disabled or troublesome youngster and provide practical help to each other at times of great stress (meals, errands, babysitting, respite shelter etc.).

Educating the public and decisionmakers. Parent organizations conduct many activities to educate and enlighten school and health care personnel, leaders in their community, the general public and decisionmakers about the service needs and rights of their children, aim to dispel myths and prejudices etc.

Changing the image of parents. When parents of children with special health care problems have written or spoken about their experiences, over and over again they testify, bitterly and angrily to the numerous ways in which they have been blamed, misunderstood and mistreated by health care professionals and others. They are made to feel guilty, victimized and discriminated against on account of their child/adolescent's health problem. All too often the expertise, skills and power of professionals is overvalued. All too often parents are viewed as overprotective or uncaring and usually incompetent.

Parent self-help organizations aim to radically change this image to one of the **resourceful, competent parent** with rights and needs that should be respected and addressed.

Advocates for parent/professional collaboration. Parents know that when they and the professionals are in conflict every one loses. Parent organizations are developing sensitivity to, and greater understanding of some of the frustrations and needs of helping professionals. Thus, parent organizations work hard to improve the ability of parents and professionals to work cooperatively to assure the best health care for their child. However they are not content to help parents play a supportive, secondary role. They are advocating a genuine, equal partnership, where each partner mutually respects the unique expertise and role of the other, but where, ultimately the parent is understood to be the person with the final responsibility and authority for the child.

Advocates for improved policy and services. Through engaging in the traditional skills of community organization, political advocacy and court action, parent organizations have helped to change local, state and federal laws and administrative rules, and successfully pushed for new, funded services. (See examples of parent organizations on p.21-23.) Among some of the substantial achievements of parent organizations in the health care arena to date are:

--Closing down state institutions that warehoused retarded and mentally ill children (e.g. National Association of Retarded Children).

--The enactment of P. L. 94-142 in 1976 and P. L. 99-457 in 1986. These are both landmark laws which not only established handicapped children's rights to education and other services, but also created new structures and procedures to guarantee parent involvement in their children's education and treatment (e.g. Federation for Children with Special Needs).

--Success in getting the majority of specialist pediatric hospitals to permit liberal/ 24 hour parental visiting, rooming-in and other family-centered policies and substantially improving parent/family visiting policies in general hospitals (e.g. Children In Hospitals Inc, Association for the Care of Children's Health).

--Raising the drinking age to 21 in nearly all the states; increasing drunk driving penalties; closing down drug paraphernalia stores in hundreds of communities (e.g. National Families in Action, Mothers Against Drunk Driving).

THE ROLE OF PUBLIC POLICY

The legal and ethical issues involved in adolescent health care are so complex and controversial that they are unlikely to be solved through definitive Supreme Court decisions. Nor does it seem appropriate, or likely, that new federal legislation should attempt to address these issues. If a model state law were developed it might help states enact greater consistency of consent and notification laws within a state, and possibly encourage greater uniformity between states. But again the controversial nature of the issue is likely to make it very difficult to achieve a consensus either within a state or across the nation. (Josephine Gittler, director, and her colleagues at the National Maternal and Child Health Resource Center, School of Social Work, University of Iowa, is beginning to work on such a model law.)

The information reviewed in this report however suggests that there are two areas within this broad subject in which both federal and state policy could play a constructive, role. First, there are a number of ways in which policymakers can help health care and social service professionals deal with the issue of parent/teen conflict on health matters in a way which strengthens and restores

families. Second, and more importantly, there are a number of legislative and administrative opportunities for policymakers to promote positive parent involvement in adolescent health.

Options to deal with parent-teen conflicts

For the most part, as we have noted, parents play a very helpful and supportive role when their teenager experiences a health problem that needs treatment. In situations where they are in conflict policymakers, as well as human service professionals, have an obligation to respond to ensure that the teenager's treatment needs are met. However, a family perspective requires that, unless it is clear that the alienation is a permanent one, the response should not exacerbate the family tension and, if possible, it should help restore communication and parental support.

There are several ways in which policymakers can help parents and teenagers avoid or resolve some of their conflicts over health related matters. Laws and court decisions which clarify mutual rights and responsibilities are only one avenue. Other potential avenues include suggesting or requiring processes that can help resolve the disputes, such as mediation; and funding family mediation, family therapy, or other community based, family support and respite services as a cost effective alternative to the placement or hospitalizations that frequently result when parents and teens continue to be "at war" with each other. Each of these avenues is discussed briefly below.

Avoidance of conflict, protection of the teenager. Statutes that provide exemptions from parent consent solve the problem of parent-teen conflicts by helping the teenager avoid the immediate confrontation with her/his parents, at least for the present. One strong rationale often cited for this approach is to protect the adolescent from bodily harm and abuse that may be expressed by an irate parent. Another avoidance strategy in the case of a pregnant minor is the judicial "by-pass" procedure, whereby a pregnant teen seeking an abortion but not wanting to inform her parent(s) goes before a judge in court. The judge then makes a determination about whether she is sufficiently mature to be able to give her own informed consent to the operation or whether, in spite of her immaturity, parent consent would not be in her best interests.

The judicial by-pass procedure has been criticized by both liberals and conservatives. Pro-choice advocates point out that to a, scared, young pregnant woman who often has little education or sophistication, the process of having to go before a strange judge can be quite traumatic. The judicial process itself may deter some pregnant teens from seeking an abortion or drive them to seek an illegal one. In some states, it has been found very effective to organize a roster of volunteer advocates who expedite the process and walk through it with the pregnant young woman (Cartoof & Klerman, 1986).

Liberals and conservatives alike have questioned whether a judge is properly qualified to determine the degree of maturity of a pregnant girl in a few minutes in the court room, and whether the judge's own personal feelings about abortion will not unduly influence his decision. Some add that, as a complete stranger, the judge has no way of independently confirming that her fears about her parent's negative reactions are justified.

They recommend leaving to the physician. the judgement about whether parents should be consulted. It is reported that the general practice of physicians, especially in the case of a young adolescent is to make considerable efforts to persuade the young woman to involve a parent, or at least another member of the family, largely because they believe she will need adult support to go through with whatever decision she makes. (Nevertheless, some pregnant teens do not see a physician but a pregnancy counselor and there is little information available about how they handle the matter.) In fact most of the younger teens do have a parent involved when they seek an abortion.

Some have suggested that as a preferable alternative to the legal by-pass procedure, the pregnant teen should be *required* to involve another adult relative or adult family friend of her choice who would function as a "surrogate" parent. This strategy has the great advantage of providing the pregnant teen with ongoing support with her decision and its aftermath. Such an adult, who knows her family, may also serve the function of helping the teen tell her parents, or confirming for the health care professionals that they should not be told.

Mediation of the conflict. Mediation could be promoted as an alternative option to the judicial by-pass procedure when a pregnant minor reports a bad relationship with her parents and in situations where a teen is out of control and warring with his or her family.

Family mediation is a growing professional field best known for its work in divorce-related disputes. However since 1981 there has been a substantial growth in the number of mediation programs helping to settle parent/teen disputes. In a survey in 1987, 63 parent/child mediation programs were identified, mostly concentrated in the northeast (Phear & Shaw, 1989). Referrals come to these programs from the juvenile/family courts, social service agencies and schools. Thus far referrals do not come from health care professionals, perhaps because the programs are not a well known resource to the health care community. Referral for mediation is often part of a court diversion program, and seen as an alternative to incarceration or placement.

These mediation programs usually use trained community mediators and the mediation generally takes between one and four sessions. The basic purposes of the mediation are to i) gain a clearer understanding of the issues; ii) increase a sense of mutual respect; ii) improve communication. In the 1987 survey programs reported that mediation is often the parent's and teen's "first real opportunity in the course of their conflict to speak candidly and rationally with one another" (Phear & Shaw, p.47).

One of the best known of these programs, The Children's Hearings Project, in Cambridge MA, serves a primarily white, low income population. At this program the disputes between parents and teenagers center on conflicts about homework, school attendance, sexual activity and pregnancy, nature of the teenager's friends, and, if the teen has a baby, how and by whom should it be cared for. Increasingly grandparents are parties to the disputes. If drug abuse and physical abuse emerges as a significant problem the mediators refer the family to other agencies. They also refer for ongoing counseling or family therapy if that seems indicated.

Community based support and respite services. Informally, and encouraged by parent self-help and support groups, situations often serious parent teen conflict are often eased when another household, of a relative or friend of the family, provides a temporary home to the troubled teen to give the family some respite from the tension and an opportunity for tempers to cool. Community runaway youth shelters can serve the same purpose. Generally the young person returns to his home or to a relatives home after only a few days in the shelter.

In the area of children's services there is a movement gaining considerable momentum to provide a continuum of services, based in the community and in the home, which help families with their children's problems which, if unmet, may result in the child or adolescent being placed or hospitalized outside the home. These developments have been addressed at greater length in previous seminars focusing on family preservation programs and child welfare reform, and the federal Child and Adolescent Service System program (see Ooms and Herendeen, July, 1989; Ooms, Beck and Herendeen, June 1990). Adolescents constitute the bulk of the population at risk of placement and unresolved issues of parent-teen conflict and family tension are often a large part of the problem.

Family oriented health practice. Most professionals working with young people in schools, health care agencies or community agencies are not trained in, or oriented to, helping teenagers deal with their family problems. In the last two decades there has been a striking growth in the numbers of health care professionals especially trained to work with the family as a unit including the new specialty of family medicine, family nursing, family psychology and the discipline of family therapy. Most of these professionals have considerable skill, when working with teenagers, in helping them communicate better with their parents about important matters and work through some of their conflicts.

Specialists in adolescent medicine and substance abuse counselors have also frequently developed these skills, and report that even when a teenager seems at great odds with his or her parents and refuses to have anything to do with them, after a few sessions, once trust has been established, they are usually grateful for the chance to try to improve their relationship with their parents which is a source of such stress for them. Clearly more professionals working with young people need to be trained to help them find ways of getting along better with their parents and other family members, and to help the family understand and support the teenager. Federal and state funding is needed before such training is undertaken on any significant scale.

Policies that promote parent involvement in adolescent health.

Policymakers can greatly help to strengthen and support parents role in their adolescent's health in the following ways:

- **Funding parent organizations.** State maternal and child health and child mental health programs together with federal demonstration grant funds can be used to directly support the activities of parent health related organizations. This is already happening in a few states (e.g. Massachusetts) and in small amounts at the federal level through the Bureau of Maternal and Child Health Special Projects of Regional and National Significance (SPRANS), through the CASSP program at NIMH and, for drug prevention activities, through the Office of Substance Abuse Prevention. There has also been some significant funding of parent organizations and consultants in the field of early intervention and special education through the Office of Special Education Programs in the Department of Education. None of these funded projects however have, as yet, emphasized the special concerns and issues of parents with adolescents and young adults. Such funding needs to be greatly expanded.and other federal and state agencies in the substance abuse field such as the Office of Treatment Improvement at ADAMHA could follow these examples.

- **Funding parent/ professional training and collaboration activities.** Federal and state funds can be used to directly fund activities which are essential to improve the sometimes adversarial relationship that can develop between parents and professionals. A model for such funding could be the Families as Allies conferences and follow up workshops and support groups funded jointly by the CASSP program at NIMH and the National Institute for Disability Research and Rehabilitation at DOE. These conferences, attended by equal numbers of parents and professionals, were designed to increase the ability of parents and professionals to plan and work together at the case, agency and system level and also began a process of identifying parents interested in forming support groups (McManus and Freisen, eds. 1986). Recognizing that parents have expertise and experience also, both in children's mental health programs and in special education parents are increasingly being hired as consultants in these kinds of training and technical assistance activities.

- **Strengthening parents' rights.** In the the field of education of handicapped children, parents rights have been given greatly increased legal and programmatic recognition. Building

on the parents rights framework initially established by P.L. 99-272, the requirements of Part H, P.L. 99-457, Education of the Handicapped Amendments Act of 1986 spelling out the rights of parents of pre-school, special needs children serve as an exemplary model to be emulated in other health program areas. In brief, in this law parents are required to participate in the assessment of their own families strengths and needs, and in the planning of their child's treatment and education, through the individualized family services plan (IFSP)

Efforts to strengthen parents rights legislatively in other federal programs should be careful, however, to include rights and participation language that specificly recognizes the continuing interest and role of parents of adolescents, and also allows for and encourages adolescents to be increasingly involved in their own health care.

- **Requiring participation of parents in policy development and program planning.** When programs administratively or legislatively establish planning and monitoring bodies parent representation should be required. If their participation is to be more than token it means that resources need to be set aside to reimburse parents for their expenses involved in attending meetings, taking time off from work (or hiring babysitters). P.L. 99-457 requires parent representation in both the federal and the state Inter-agency Coordinating Councils. These are bodies which play a critical part in the effective implementation of this ambitious new federal law.(see Ooms and Herendeen, March, 1990). If this type of participation was spelled out in a program that served adolescents, teenage representatives should also be included along with parent representatives. This kind of consumer involvement in community health needs assessment and planning has been occurring at state and local level in a few adolescent health initiatives occurring under a Maternal and Child Health umbrella, for example in Colorado. (See Ooms and Herendeen, July 1989.) It is also incorporated into a new children's mental health proposal, as discussed below.

New Proposal: Children's and Communities' Mental Health Systems Improvement Act, HR 5306. This bill was introduced in July by Rep. George Miller (D-CA), Henry Waxman (D-CA), William Goodling (R-PA), Steny Hoyer (D-MD) and Doug Walgren (D-PA) and, as of mid-September, had 64 co-sponsors. The bill would provide the only pool of federal dollars available to directly expand community based children's' mental health services. The new bill would provide funds for a broad range of community-based services (excluding inpatient hospital or residential programs of more than 8 beds). States would be awarded five year grants on a competitive basis and would be required to provide a 25% state match for the federal money. If fully funded, at least 10 states would be funded the first year for a total of $100 million.

An ad hoc coalition of national child advocacy and mental health groups spearheaded by the National Mental Health Association were involved in drafting this bill. "If the proposal passes, states would be required to demonstrate parental involvement in planning and follow the principles of CASSP in developing local systems of care in order to receive funding" (Florida Mental Health Institute, Summer 1990).

The bill states that "a system of care....will develop and implement an individualized plan of services for each child admitted to the system, and that the plan will be developed and implemented with the participation of the family of the child involved and, unless clinically inappropriate, with the participation of the child,"(Sec. 1926.(a)). And later in the bill it requires that the state set up a mental health planning council "will include as members of the council a ratio of parents of children with serious emotional disturbances to other members of the council that is sufficient to provide adequate representation of such children in the deliberations of the council." (Sec. 1927 (d)).

SELECTED PARENT SELF-HELP ORGANIZATIONS.

We list below a selection of the many parent self-help organizations which are active in the area of child and adolescent health.

CANDELIGHTERS Childhood Cancer Foundation

Candelighters is a non-profit organization which functions as the coordinator, information clearinghouse and educational arm of the 300 parent groups and contacts throughout the world. Local parent groups serve as an informal forum where parents share feelings, experiences and information on family life with a child with cancer. Some groups have youth auxiliaries for teenage cancer patients and teenage siblings of children with cancer.

Local groups sponsor crisis phone lines, buddy systems, parent-to-parent contacts and social functions and may also provide practical assistance to families such as transportation, babysitters or help in the hospital. They also provide speakers, publish newsletters and information about local resources.

Some groups are engaged in political advocacy at state level and the Washington group is a registered lobbyist and monitors federal legislation.

Contact: Grace Monaco or Julia Sullivan, The Candelighters Foundation, Suite 1011, 2025 Eye Street N.W. DC 20006 (202) 659-5136

CHILDREN IN HOSPITALS.

Children in Hospitals is a non-profit organization of parents and health care professionals. It seeks to educate all those concerned about the needs of children, teenagers and their parents for continued and ample contact when any members of the family are hospitalized. It encourages hospitals to adopt flexible visiting policies and provide living-in accommodations whenever possible.

Contact: Barbara Popper, 31 Wilshire Park, Needham, MA 02192. (617) 444-3877 or (617) 482-2915

FEDERATION FOR CHILDREN WITH SPECIAL NEEDS

The Federation is a national network of a number of organizations concerned with children with specific chronic illnesses and disabilities. It operates several programs that aim to provide information and technical assistance to parent organizations and individual parents. Among these are:

Parent Training and Information Project (PTI) is a federally funded network of over 50 centers offering a variety of statewide services to parents of special needs children and the professionals who serve them. The services include workshops, a quarterly newsletter, resource library and speakers bureau.

Technical Assistance for Parent Programs (TAPP) was originally established under the 1983 Education for the Handicapped legislation and refunded under P.L.99-457. TAPP provides technical assistance to the PTI centers through four regional centers in Tacoma, Minneapolis, Concord, NH and College Park, GA. Throughout the many services the TAPP centers provide

there is a special emphasis on reaching out to those families whose children are least likely to be served.

Collaboration Among Parents and Health Professionals (CAPP), National Parent Resource Center. This program is implemented in conjunction with the TAPP and PTI projects. CAPP's purpose is to develop a parent organized, nationally coordinated resource system designed to further the goals of family-centered, community based, coordinated care for children with special health needs and their families. Four regional centers and eight parent resource consultants are located around the country.

Contact: Betsy Anderson or Barbara Popper, Federation for Children with Special Needs, 95 Berkeley Street, Suite 104, Boston MA 02166 (617) 482-2915.

FEDERATION OF FAMILIES FOR CHILDREN'S MENTAL HEALTH

The Federation of Families for Children's Mental Health is a national parent-run organization focused on the needs of children and youth with emotional, behavioral or mental disorders and their families. The organization grew out of a series of meetings held after the first Families as Allies conference sponsored by the Portland State Regional Training Center in 1986. The Federation was formally incorporated in 1989. Many of the Board members and others involved in the organization are members of active parent groups and state organizations.

The Federation's mission is to provide national leadership and advocacy for full citizenship, support and access to community based services for all children and youth with these disorders and their families. It also aims to provide information and advocacy about the full range of research, prevention and treatment services needed by these children and their families. The Federation publishes a newsletter, *Claiming Children*, The first issue, Spring 1990, has a list of names and addresses of representatives in each state. President: Barbara Huff, c/o Keys for Networking, Inc. 700 S.W. Jackson, Suite 100 A, Topeka, KS 66603 (913)233-8732

Contact: For membership information and the newsletter write to 1021 Prince Street, Alexandria, Virginia 22314 (703) 684-7710.

National Alliance for the Mentally Ill, Child and Adolescent Network (NAMI-CAN)

NAMI-CAN is a grassroots self-help support and advocacy organization of parents and friends of seriously emotionally disturbed children and is affiliated with its parent organization the National Alliance for the Mentally Ill. In addition to sponsoring local member support groups, it focuses on public education and advocacy for improved understanding of children's mental illness and increased funds for services and research.

Contact: National Alliance for the Mentally Ill, 2101 Wilson Boulevard, Suite 302, Arlington VA 22201 (703) 524-7600

NATIONAL FAMILIES IN ACTION

National Families in Action (NFIA), founded in 1977, is a parent-run organization whose purpose was to create and lead a nationwide, volunteer, grass-roots movement in which ordinary citizens organize to prevent drug abuse in their families and in their communities. Its purpose is to educate

society about the dangers of drug abuse by disseminating accurate and timely information. The organization houses and operates an information clearinghouse, the National Drug Information Center which publishes a quarterly newsletter, *Drug Abuse Updates* which reports regularly on new research and the activities of federal agencies, and state answers requests for information and for treatment referrals. Its information is designed to assist hundreds of local and state parent organizations which conduct advocacy activities at local, state and federal level to change the community environment which serves to foster adolescent and adult drug abuse.

A grant from the federal Office of Substance Abuse Prevention is enabling NFIA to engage in a demonstration project to help Atlanta families who live in public housing to organize local drug prevention groups to address the devastation crack has brought to the inner city.

Contact: Sue Rusche, National Families in Action, 2296 Henderson Mill Road, Suite 204, Atlanta GA 30345 (404) 934-6364

TOUGHLOVE INTERNATIONAL

Toughlove is a self-help organization for parents of teenagers with disruptive, defiant or drug-abusing behaviors. It sponsors, and provides technical assistance to,hundreds of local parent run groups all over the world. It is a combination of philosophy and action which, together, can help families and neighborhoods to change. It is a crisis intervention program which uses structured group meetings to support parents and spouses in demanding responsible cooperation from out-of-control family members.

At group meetings parents are helped to reassess their own situation and develop a structured, step by step program for the next week. Other parents and group members often play an active role in helping parents accomplish the steps (e.g. they may confront the troubled youngster, or provide him/her with temporary shelter). Toughlove groups work actively with professionals, schools and other community agencies to enlist their understanding and cooperation.

Founded by two socialworker/parents, David and Phyllis York, Toughlove, International is the nonprofit organization that coordinates and provides services and support to the network of Toughlove groups. The service center maintains a hot-line referral system to over 500 local groups; publishes a newsletter; publishes and distributes books, manuals, videotapes; trains area representatives; and helps local groups get started. The organization has several groups in Hispanic communities, and its materials are translated into Spanish.

Contact: Teresa Quinn, Toughlove International, P.O. Box 1069, Doylestown, PA 18901. 1-800-333-1069.

ADDITIONAL RESOURCES

The following organizations are a resource for materials and further information on parent/family involvement in child and adolescent health:

Association for the Care of Children's Health
7910 Woodmont Avenue, Suite 300
Bethesda, MD 20814
(301) 654-6549

Beach Center on Families and Disability
Bureau of Child Research
University of Kansas
4138 Haworth Hall
Lawrence, KS 66045
(913) 864-7600

Center for Children with Chronic Illness and Disability
Maternal and Child Health
School of Public Health
University of Minnesota
Box 197-UMHC
420 Delaware Street S.E.
Minneapolis, MN 55455
(612) 626-6931

Children's Hearings Project
A Family Mediation Program
Cambridge Family and Children's Service
99 Bishop Allen Drive
Cambridge, MA 02139
(617) 876-4210

Child and Adolescent Services System Program (CASSP)
Technical Assistance Center
2233 Wisconsin Avenue NW
Washington, D.C. 20007
(202) 338-0861

National Center for Youth Law
Adolescent Health Care Project
114 Sansom Street, Suite 900
San Francisco, CA 94104
(415) 543-3307

National Center for Youth with Disabilities
Adolescent Health Program
University of Minnesota
Box 721-UMHC
Harvard Street at East River Road
Minneapolis, MN 55455
(612) 626-2825

National Maternal and Child Health Resource Center,
College of Law,
University of Iowa,
Iowa City, IA 52242
(319) 335-9067/9537

Research and Training Center on Family Support and Children's Mental Health
Regional Research Institute
Portland State University
P.O. Box 751
Portland, OR 97207
(503) 725-4040

Research and Training Center for Children's Mental Health
Florida Mental Health Institute
13301 North 30th Street
Tampa, FL 33612
(813) 974-4040

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Prepared by Theodora Ooms
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